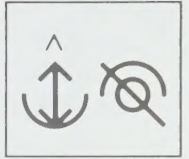


COMMUNICATING TOGETHER



A QUARTERLY MAGAZINE ABOUT AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

VOLUME 9, NUMBER 2

JUNE 1991



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TELECOMMUNICATING WITH BLISSYMBOLS

ANN KENNEDY and KAREN WATSON

Ann Kennedy is Director of the Easter Seal Communication Institute (ESCI) and Editor of Communicating Together. Karen Watson is an Augmentative Communication Assistant at ESCI. For several months in 1990, ESCI was involved in conducting a field trial of the software developed by IDON Corporation of Ottawa which allows Blissymbol users with computers to communicate via telephone connections. Karen was active throughout the project interacting on-line with the participants and visiting them in their homes to observe them using the system. In the following article, Ann and Karen report on some of the highlights of the Toronto field trial.

During the month of July, the Bliss-Tel Network was buzzing with news. Kari provided daily updates that she was "going to be an aunt very, very soon". All participants on the Bliss-Tel network became very anxious waiting to hear news from Kari. Finally the message reached every one. "I am an aunt to a baby boy. His name is Justin Barry." This was just one of the many interesting "conversations" that took place on the BlissTel system during the field trial last fall.

Some of you may remember Kari Harrington's article "I'm in a Field Trial Now" which appeared in the September 1990 issue of *Communicating Together*. In it she told of her excitement at being involved in the trial and evaluation of software that would allow her to "talk" with her Blissymbol friends by using her computer, modem and the telephone line. Kari used a Macintosh throughout the trial, but some of the others were using IBM computers.

How it all Began

Towards the end of 1987, the IDON Corporation in Ottawa received word that its proposal to the Department of Communications and Supply and Services of the Government of Canada had been accepted. The goals of the project were to produce a computer

to computer communication coding standard for the transmission of Blissymbols, and to build a computer based Blissymbol Telephone (BlissTel) application that used the communication coding standard to transmit Blissymbols.

This project grew out of an earlier one by IDON in 1986-1987 which investigated the feasibility of developing a telecommunication system that combined advanced electronic technology with an augmentative communication system. The first project, called Blisscom, used Apple computers and a limited vocabulary of 200 Blissymbols. The evaluation and field trial of the Blisscom project was carried out at the Faculty of Education, McGill University of Montreal.

The BlissTel project expanded the scope of the first, to allow telecommunication of all Blissymbols using a two byte standardized code between different kinds of computers, in this case Macintosh and IBM. Having all 2500 symbols available within the software gave the potential for conversations on a much broader range of topics.

IDON was grateful to IBM Canada for donating some of the computer

equipment, and to Apple Canada who loaned some computer equipment, since this major item was not covered by the government grant.

Blissymbolics Communication International (BCI) was involved throughout, advising about the technical aspects of the symbol system. ESCI's role was to develop assessment tools for use in the field trial, train participants in the use of the software and work with them throughout the trial period as the system was evaluated, and based on the evaluations of all involved, to make recommendations to IDON.

Choosing the Participants

The Toronto field trial of BlissTel began officially on May 5, 1990 and ran through to the end of December. Naomi Gibson, then director of ESCI's Educational Service Program served as site co-ordinator. She was assisted by ten others; two assistants, three trainers, and five facilitators. Central to the whole trial, of course, were the participants themselves who actually used the software to communicate with each other and with the training staff.

Though the trial began in May,



Cathy Fairley assists Aaron Shelbourne as he talks with Mary Frances Laughton (left), Department of Communications, and Naomi Gibson (right), ESCI, site co-ordinator.

there were months of planning ahead of time. An assessment tool was developed to help in the selection of suitable participants for the project. There were several criteria that participants had to meet to be eligible to take part. Firstly, they had to be proficient in the use of Blissymbols and familiar with computer technology. Secondly, they needed to have common interests with the other participants. Lastly, for time and expense reasons, they had to live within the greater Toronto area.

Three of the participants selected had been classmates years ago in one of the early Blissymbol classes at the Ontario Crippled Children's Centre school (now Hugh MacMillan Rehabilitation Centre, HMRC). Since then they have gone in different directions, and they enjoyed the opportunity the trial gave to renew friendships.

The first, Kari Harrington, needs no introduction to *Communicating Together* readers. Kari uses an Epson with Real Voice as her regular communication now, but still keeps her Blissboard as back up. She is very comfortable with computers, having used an Apple IIe for many years. She uses direct selection with her left hand on the

keyboard. At the time of the trial, she was still living at home with her family, and her work station was set up in her room there.

Joe Jessop was another former student from HMRC. He continues to use a Blissboard, and has developed good spelling skills as well. For the past several years he has been working at a sheltered workshop and his work station was installed there. Joe lives at home with his family.

Ann Running is the third of the group to have attended HMRC. She presently lives in a group home for people with physical disabilities. She has many words on her communication board, and uses them along with her Blissymbols. She uses eye gaze for "yes" and "no" to access symbols, words or letters on her communication board. She attends a literacy class in an adult education program in Toronto. Ann has had several years of computer experience, and for this trial, had her equipment set up in her room. A mouse was adapted to enable her to access the system by means of a head switch.

Aaron Shelbourne learned Blissymbols when he was a teen-ager at Bloorview school, and continues to use them as his primary means of

communication. He uses a head switch and a scanning system to access the computer, but finds it much slower than using his communication board. Aaron lives in the same group home as Ann, and is participating in the same adult literacy program.

Susan Odell is a very proficient symbol user with an extensive communication board, which she points to with good accuracy. She lives independently in an apartment, contracting for what attendant care she needs throughout the day. She, too, has used computer technology for many years, particularly an Apple IIe with the Talking Blissapple program. For the field trial she had a Macintosh SE system installed in the apartment, and accessed it using two foot-operated single switches adapted from her Apple system.

One last Blissymbol user, Chester Kwaka, participated in the early stages of the field trial. He was very enthusiastic and looked forward to the project until he became seriously ill in early summer. We all felt a great sadness and sense of loss when we learned of his death in the early fall.

Adding a national dimension to the trial late in the fall, was the "sign-on" of Elaine Drover in Newfoundland. Elaine is a very experienced Blissymbol user who has used an Apple computer and the Talking Blissapple program extensively. She has visited Toronto in the past, and knew several of the participants. The federal government's Department of Communications co-operated to make it all happen by providing the telephone line hook-up to the host computer at IDON in Ottawa.

Elaine was quick to introduce herself to the BlissTel network. When she failed to hear from the trainers or participants, she prompted all participants, "Did you get my message from me, Elaine Drover? I am anxiously awaiting to hear back from you."

Getting Started

Training began in earnest in early May, when Bill Lalonde from IDON arrived in Toronto for four days to instruct Naomi and the trainers, Cathy Fairley, Donna McGhie-Richmond and Jack Sim in the use of the software and the various



Susan Odell accesses the Macintosh computer using two foot-operated single switches.

functions of the system. They worked on an IBM PS30 system and a Macintosh SE linked together to simulate a network which permitted the use of the Talk feature of the system. All the people involved in the trial — trainers, participants and facilitators — got together on Bill's last afternoon in Toronto to discuss the trial and have questions answered. It was the first time the participants had all been together and for some it was a chance to renew acquaintances with old friends, as some had not seen each other for years.

For the rest of the month the trainers practised with the software to become familiar enough that they could teach others how to use it. With the hardware installed in each participant's home or workplace it was time to start training the participants and facilitators. By the end of August, everyone was trained, ready and eager to "talk".

Software Bugs Were No Deterrent

We were all pleased to find that the participants learned to use the system with ease. As with most new software programs, there were "bugs" but that didn't stop our people. The most frustrating thing for those who were *not* disabled was the slowness in finding the wanted symbol. Perhaps, because communication is always a slow process for those who are unable to speak, this did not seem as big a problem to them.

The system has an electronic mail feature, and most found this the most satisfactory way to communicate. With it, a message could be left by the sender on the host computer (at IDON in Ottawa), to be picked up later by the receiver at his or her convenience. This saved tying up the telephone lines for long periods using the TALK feature, because of the time needed to create a message. Maybe some of the spontaneity was lost, but it was more time efficient and less frustrating.

Social Get-togethers Added Fun

Throughout the trial, the trainers visited the participants on a weekly or twice weekly basis to check that everything was working well, and to problem-solve around some of the difficulties that were encountered.

The trainers were all actively involved on the system too, communicating with messages to the participants. For Sherri Parkins, ESCI Augmentative Communication Instructor, and Kari Harrington, BlissTel provided a way for them to plan a sign language class in which they were both involved.

Since some of the young people were not too well acquainted, Naomi and the trainers gave suggestions about things they might all talk about in order to find out more about each other. Joe Jessop and Aaron Shelbourne discovered a mutual interest in pubs, and had fun planning an outing to a local drinking establishment! Elaine Drover expressed her interest in the World Figure Skating competition.

Communicating over the phone lines was not the only way for participants to re-establish friendships. Monthly meetings were arranged for them to discuss the computer system, and suggest topics they might talk about and events they might plan. The young men were interested in sports, but Kari didn't seem to think the women were interested in that! We were fortunate to have Bill Lalonde from IDON and Mary Frances Laughton from the Department of Communications in Ottawa attend several of these meetings. It was a chance for them to get to know the participants and to hear first-hand their comments and concerns about the system.

Illness plagued the field trial throughout. There was only one monthly meeting when the whole group managed to attend. Sickness also meant there was considerable lost time in an already short trial period.

The End Came Too Soon

The last meeting took the form of a Christmas party and fortunately everyone was able to make it. It was a pot-luck luncheon generously hosted by Naomi in her apartment. Even though her living room was large, five wheel chairs and a Christmas tree had it overflowing. Gifts were exchanged and a good time was had by all. Bill Lalonde announced that IDON Corporation would maintain the BlissTel system and electronic mail for a little longer even though no technical support

could be provided.

Throughout the field trial Sherri and Karen had visited all the participants and videotaped them using the BlissTel software and giving their personal comments about it. Viewing the videotape after months of anticipation proved great entertainment for the Christmas party.

In reviewing the trial and drawing conclusions, it was agreed by participants and trainers, both, that the time period was too short. Everyone was just getting really comfortable both with the system and each other when the project ended. Even though there were concerns and frustrations, the participants became increasingly enthusiastic about the potential and the possibilities that BlissTel brought into their lives, the benefits of being able to interact independently with others near and far via telecommunications.

Looking to the Future

Our part in BlissTel is now over, but the second phase of the Field Trial is underway in Ottawa with nine participants. We all hope that once the Field Trials are complete, IDON Corporation will be able to make the necessary software changes to allow BlissTel to be a viable communication medium for Blissymbol users. □

Join ISAAC Now

The International Society for Augmentative and Alternative Communication (ISAAC) offers four types of memberships:

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- Contributing Membership
- Corporate Membership

Members of ISAAC are entitled to reduced rates for: *Communicating Together Communication Outlook Augmentative and Alternative Communication* (AAC journal)

For membership application and other information about ISAAC write ISAAC, P.O. Box 1762, Station R, Toronto, Ontario, Canada, M4G 4A3.

The Bad and The Good

KARI HARRINGTON



Kari Harrington was in the original Blissymbol class of 1971 at the Ontario Crippled Children's Centre. She attended James Robinson Public School in Markham and then Langstaff Secondary School in Richmond Hill. Aside from writing this column, she works part-time for the Easter Seal Communication Institute, making presentations to schools and other organizations promoting public awareness of alternative and augmentative communication and the special needs of those without functional speech. Kari has written many poems and stories and is currently completing her first novel, Don't Shut Me Out. She has recently taken a step to independent living, moving from home to Participation House in Markham, Ontario.

I had a recent stay in hospital which was quite an experience, to say the least! When you have to have an operation, there are always things you just want to forget about, but there are also good things that you will always remember.

Before my brain surgery, I became really frightened, wondering what I would be like afterwards, but when I woke up, I knew I was still ME. It had taken twenty-six years to become what I am, and it was scary to think I might wake up different.

Having my head shaved was not as bad as I thought it might be. I didn't look too awful! Besides, lots of people said I looked like Sinead

O'Connor, the Irish singer, and although I didn't even know who she was, the way they said it made it sound pretty good.

A New Nonspeaking Friend

Another of the good things I will always remember is sharing experiences with my last roommate, Shelley, who is twenty-one years old and cannot speak out loud because of a disorder known as dystonia.

Dystonia is a hereditary condition which, very simply put, causes muscles to lose their resilience and elasticity, and in time, lose their ability to contract altogether. There are many, complicated variations of dystonia and I am not sure which type Shelley has, except that her disability has been progressive and now her whole body is becoming stiff, very much like a person who has severe spastic cerebral palsy. Shelley's older brother has dystonia, too. However, his condition is localized to just those muscles which control his voice output and right now he is taking drugs which are helping him.

Shelley seemed to be fine until she was eleven years old and then her voice began to sound strange and it was hard for her to get the words to come out at all. Her lips moved in the same way as they always had, but her voice deteriorated. The doctors her parents took her to did not know what was wrong, and the school officials were sure Shelley's lack of voice was caused by emotional problems. Her parents were advised to take her to child and family counselling clinics. The lack of proper diagnosis reminds me of the way it was years ago for many of us who have cerebral palsy. Shelley's parents, like ours, were made to feel they were somehow responsible, that they were not being good parents and in some unknown way, were not giving their child what she needed to develop properly. Her parents, again like ours, followed every suggestion offered to them by psychologists, teachers and doctors — including getting a dog for Shelley to practise "talking to!"

Not too long after this, Shelley

began experiencing problems with the motor function throughout her body, and she was finally referred to a doctor who recognized her condition. As a matter of fact, this doctor is working with others in Boston who are attempting to isolate the gene that causes dystonia. Some of Shelley's relatives also have dystonia in varying degrees. They all came to the hospital to give blood to be sent to Boston to use in the research.

When I met Shelley, she was unable to sit at all. After each meal her Dad or Mom would slide her to her feet, give her a bear hug from behind and "walk" her for a few minutes to help her digest her food and get rid of gas. (The way she "walked" was just like I can do with my Mom or Dad, only for a different reason.) The rest of the time Shelley just has to lie down. She has a "Fortress" too, but hers is a motorized banana cart while mine, of course, is a chair.

The unfortunate part is that she uses her cart mainly for getting to and from doctors' appointments. She has a few problems which affect her going out anywhere else. Her condition has caused her neck to arch backwards. This is painful and prevents her from lying comfortably on her stomach to drive the cart. Also, she has excessive secretions in her mouth which she must use a suction device to remove because she has problems swallowing them all. In addition, she has had a tracheotomy and this must be dealt with too. By the time I left the hospital, the doctor had done some sort of 'block' in her neck which would help the arching problem and the next day, they were going to remove two of her salivary glands to help control the excess of secretions in her mouth. Hopefully, with these things done, she will be able to get out of the house more and enjoy some new experiences.

Communicating with My Room-mate

Shelley remains able to move her lips in a controlled way that allows people to 'read' what she is saying. If someone gets stuck, she spells out

the word. It works well most of the time, but of course, not so well for two people lying almost flat on their backs five feet apart. Once I got back to using my Epson with Real-Voice again, we had one half of the problem solved. The Moms had to take care of relaying Shelley's communications.

Shelley said she had seen some curly-headed girl using a voice output communication device on the

Easter Seal Telethon a few years ago and thought the voice was horrible. She said she would rather not have a voice at all than sound like that. Shelley quite liked *my* voice though. (She didn't recognize that I was the same girl with a new voice and a new hair do!) Who knows? Maybe when Shelley starts getting out a lot more, she will want a voice of her own too, and maybe we will even have the same voice! □

Editor's Note:

In the next issue of the new *Communicating Together*, Kari and her mother Ruth Harrington will be editing the section "Living". If you have any material you want to share with them for this new column, contact:

Kari Harrington
Participation House
8 Butternut Lane
Markham, Ontario L3P 3M1

RESEARCH INTO PRACTICE

Requesting

BARBARA REID



Barbara Reid is a consultant with the Easter Seal Communication Institute. She has been involved in the field of augmentative communication since 1976, first in England and then in Canada. She has worked in research and training as well as consulting, and has co-authored two books and several articles on augmentative communication.

In this column, we will return to the challenge of teaching augmentative communicators to use the skills which they have learned. In a previous issue (*Communicating Together*, Vol. 8, No. 3), we looked at some research by Dianne Angelo and Howard Goldstein on teaching students to use their communication displays to ask questions (e.g. "what's in the bag?", or "who is at the door?"). In this issue, we will look at two studies

which address an even more basic skill — requesting objects or actions (e.g. touching a picture of a toy car to indicate "I want the car"; signing "please + help" to ask someone to open a locked door).

The first study, by Elizabeth Kozleski (1991), used an expectant delay procedure for teaching requests. The procedure used is deceptively simple. The teacher presented the student with some items of interest, presented a communication device which incorporated photographs of the items, established eye contact, "asked a question" using only facial expression (e.g. raised eyebrows), and waited 45 seconds for the student to respond.

At no time during the procedure did the teacher say anything, or physically prompt the student to use the communication device. In our role as augmentative communication consultants, my colleagues and I have found that this restraint on the part of the speaking partner, as well as the ability to wait for a response, have been difficult skills to teach (and even to model!). But the results of Kozleski's research suggest that these skills are well worth acquiring. Two students took part in her study. Both had severe cognitive and physical disabilities, but were able to communicate through gestural, vocal and behavioral signals (Oscar) and conventional head signals for "yes" and "no" in response to questions (Melissa). When positioned appropriately, both students could use simple switches to activate communication devices.

One important feature of this study was the care that was taken to design the experimental materials and procedure around the interests and abilities of the students. Three high interest items were identified for each student, from a wide range of objects with which they had the opportunity to interact. The length of delay used in the experiment was established by measuring the time it took for each student to respond to environmental cues. On average, the students took about 44 seconds to respond to a cue such as "It's time to go outside" by smiling or looking at the door, or to respond to a preferred object by touching it.

Individual Delay Times

Whether we are preparing to conduct research, teach new skills or simply communicate with students who are nonspeaking, their average response times are important pieces of information. They could be written into the instructions on a communication display. (I communicate by pointing to a symbol with my fist. Please count silently to 30 after you ask a question to give me time to reply.) This could help new communication partners who might otherwise fire off a series of questions and assume the student was incapable of an answer if he or she gave no immediate reply.

The time delay procedure and picture device used by Kozleski were very successful. Both students improved from under ten percent of self-initiated requests during base-

line trials to over eighty per cent by the end of the experiment. It is interesting that both students enjoyed this degree of success even though Oscar had not attained sensorimotor stage five, often cited as a cognitive prerequisite for the use of symbolic communication. Kozleski discusses the importance of this finding in the context of selecting (or not selecting) students for communication training. She also points out that the expectant time delay procedure teaches children to use the requesting function of language directly, unlike other approaches which teach the labelling function first and then expect the student to generalize from using a symbol as a label to using the symbol to make a request.

The second study, by Lyle Romer and Beth Schoenberg (1991) also taught students to request, rather than to label or simply answer questions. Their two students, both adults, had developmental disabilities and some degree of deaf-blindness. The older woman was able to use sign language, speech and tadoma, while the younger one could use tactile sign language and gestures. Despite their sign language skills, the women rarely initiated communication.

Romer and Schoenberg conducted their intervention with residential support staff, so that the women could learn their new skills in a natural setting (their own home) with familiar communication partners. Two pairs of staff were trained. The first pair had several years experience as residential counsellors; the second pair had about six months experience. The first support staff pair worked in the residence during the first baseline and experimental phases of the study. Then they were replaced by the second pair of staff, allowing the researchers to record a second baseline and add a second experimental phase.

Interruptions to Prompt Requests

Just before their respective experimental phases, each pair of staff was trained in behaviour interruption strategies. In general, the procedure involved interrupting a student once she had begun a particular activity, and requiring that the student communicate in order to have the activity continue. Interruptions could be

physical, with the staff member blocking the student's way, could involve the presentation of new activities for choice-making, or could use "sabotage strategies" such as materials missing from their required places, or offering incorrect, broken or nonfunctional materials.

Romer and Schoenberg obtained data both for support staff and students. Neither pair of support staff used any interrupted behaviour chain strategies during their respective baseline phases, but both pairs showed use of the strategies once they had received training. The experienced staff used the strategies more frequently than new staff, a finding that also relates to the students' performance.

The students' data show a clear effect of the staff training, with both total requests and self-initiated requests increasing once the intervention phases began. The students also reflect differences between staff pairs, with higher request rates while interacting with the more experienced (and perhaps more familiar) staff.

Both studies offer teaching strategies to help students learn to initiate communication. They offer alternatives to teaching students simply to label objects and activities in the hope that the label can later be used as request. They also suggest that we look at the speaking partner's role, and change from leading with a spoken question to leading by silently setting up or interrupting an activity. Whether we are concerned about students who respond appropriately to our questions but rarely communicate spontaneously, or students who have no formal system of communication in place, the expectant time-delay and behavioral interruption procedures can help them gain control over their environment. □

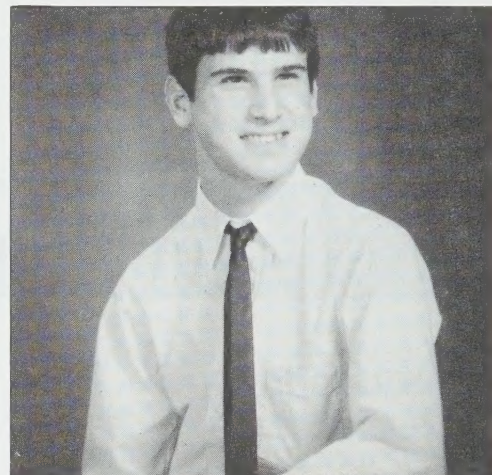
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TEACHING

Successful Integration from a Student's Perspective

VICTOR VALENTIC



Victor Valentic is a student at Hill Park Collegiate in Hamilton, Ontario. He presented the following talk at a recent meeting of Augmentative Communication Rounds, a group of people associated with AAC who meet regularly in the Southern Ontario region to keep abreast of current trends in the field. Victor's presentation was part of a panel on "Successful Integration". His presentation on his own integration into the regular school system shows humour, perseverance and insight. Victor has completed Grade 12, and, on graduation from high school, hopes to study computer science at a community college.

I will begin by stating I believe I have been successfully integrated for my education in regular public schools. To me successful integration has meant being allowed to attend my local neighbourhood school, placed in a regular classroom with students who are able-bodied, and with a variety of teachers who presented lessons to all their students using helpful teaching methods which enabled me and my fellow classmates to learn. The acceptance of my alternate means of carrying out work, the creative teaching allowed in many classes, and the adaptations to the regular curriculum used by

teachers, all contributed to my success. Similarly, utilizing classmates to assist me in areas where I needed help was a very important ingredient to my being able to improve skills and learn some physical tasks which, had I not been expected to do them, I would never have mastered.

Interaction Adds the Human Ingredient

Interaction with my classmates was the human side to my education. I have a funny story to tell regarding my educating the other students. While we all were kids about the same age and size, some of us were quite different — me with my leg braces, orthopaedic boots and word board and Robert who had black skin, curly hair, and a highly inquisitive personality. It never failed but that when he was the buddy chosen to accompany me to the washroom to help me open and close the door (because I had even worse balance in my younger years), he always tried to peek at me under or over the cubicle walls. I guess he was just checking to see if we both went to the washroom the same way. One day, he was successful; he startled me by peeking under the wall. Needless to say, the floor needed an extra clean up that day. I will never forget the look on his face!

Factors which contribute to successful integration involve choice of teachers, school and technology as well as individual determination. Firstly, you must have teachers who are willing to teach students who are disabled. A good teacher will be able to cope with varying the style of his or her teaching subjects. There must also be back-up resource and support people who can give tips on teaching areas that seem to be presenting difficulties to the student and teacher. The teacher must also be receptive to listening to a child give advice about the appropriate solution to a problem. This ability, to believe that a child might know something that they don't, is often very difficult for adults.

Secondly, it is wise to choose a school that your neighbourhood friends attend. I was no surprise to the majority of my classmates; they had known me and how I did things for many years before I became a fellow classmate. They also were able to explain about me to any new students who had never met me or had any exposure to a person with disabilities.

Thirdly, the means of getting to and from school and the school layout are factors that you have to check carefully. If a child is to be allowed independence in attending school and in trying to do things close to what is considered the norm, he should also try to get to and from school on his own and be able to move freely around the school premises. In my case, I was very fortunate that the first school I attended was within walking distance for me, and I walked back and forth four times a day, weather permitting. The school was also basically a one-floor plan except for one wing in which I happened to have my classroom for two years. There were ten steps which I had to go up and down when I went out for recess, or the washroom, or to the gym. I had to reassure the teachers I could do the steps on my own, but somehow they always followed me up and down. The kids were so helpful, sometimes too helpful; I had to control myself from pushing them away.

Technology Choices Are Important

Making wise use of the technology which is now available is also absolutely essential for a person like me to be able to continue on through high school in a regular class setting. Electric wheelchair, laptop computer, voice synthesizer, ultralight computers are some examples of the modern technology I have been using in recent years. Individual determination is another important factor in successful integration. In my case, there were no barriers to my being integrated even at the young age of seven, although my physical abilities were

way below what most kids were able to do naturally. Once the decision about my education was made by myself and my parents, plans for how to manage that education were soon underway, and still are today as I complete high school and head for college. We have a formula; as problems present themselves, solutions are sought, and, at times, we have learned that you never give up, just keep on trying.

However, since I have always had the acceptance of ninety percent of my classmates, I was able to overlook mean comments and I was taught by my parents, "in one ear and out the other". Especially at high school, you can't be sensitive — at least not at Hill Park where I attend now. It is a two-floor high school with five different staircases; only one of these is easy for me and it took a lot to convince the school principal that I was not a hazard going up and down carrying my book bag. I have found I have to be aggressive and the students who stop mid-stair to chat, run the risk of me crashing into them because I hang onto the rail and when I am on the move I can't stop my walking so I may push anything in my way. Some get grouchy at me but I think "so what".

Integration works best for a person with a good mind who is willing to work every day in every grade. This willingness to cover each subject to its fullest is important especially for a disabled person who must always do things the hard way so long as it is the possible way. Disabled people must have the foresight to pursue their own individual schooling goals which they set up when they are young. Today, I am happy to say I have been integrated in the school system, but I am proud to say that I am integrated in life. □

Have You Moved?

Please remember to let us know your new address. If possible send an address label from a past issue. Mail to:

Communicating Together
250 Ferrand Drive,
Don Mills, Ontario, Canada
M3C 3P2

Getting Ready for the Revolution

GEB VERBURG



Research and Publications is written by Geb Verburg, who has been involved in the field of augmentative and alternative communication (AAC) since the mid-seventies. A cognitive scientist, Mr. Verburg is currently working as coordinator of the research in cognitive development program of the Rehabilitation Engineering Department at the Hugh MacMillan Rehabilitation Centre, Toronto.

This column is based on a presentation I gave to a long term planning meeting of members of a provincial branch of the Canadian Rehabilitation Council for the Disabled. I was asked to speak about "The Responsibility of Persons with Disabilities toward the Community". I will share the ideas of that talk in this column and look at people with disabilities and society, and what society expects from persons with disabilities. I want to touch on responsibility, on employment and on a revolution which is beginning; and on the deep and real changes that are occurring in the attitudes of persons with a disability. Perhaps the changes do not happen fast enough, and they may not be pervasive enough, but they are occurring nevertheless. The strong convictions that drive this revolution will undeniably change how AAC and rehabilitation services are going to be provided. Finally, I will mention some research data that show the existence of a serious bias

in able-bodied persons' perception of persons with a disability then conclude by presenting some general approaches and give examples of specific little revolutions.

Paradoxes

Dr. Jim Vargo's article entitled: "Perspectives on a different world; People with disabilities in the 21st Century" appeared in Rehabilitation Digest (Winter 1990). In it Vargo identifies a number of paradoxes or double messages which are continually sent to persons with disabilities. (1) Medical and rehabilitation professionals encourage compliant and docile behaviour, yet wish people to be independent. (2) Institutions continue to receive vastly more funds than do independent living centres (ILC), yet here too, the dominant priorities are said to be focused on community based programs. (3) Society continues to expect very little of people with disabilities (some funding rules discourage part-time employment), and at the same time we also maintain the ideal of employability.

The final paradox concerns the perception of Quality of Life, or QoL. As Vargo points out "Many believe that life is tough for people with disabilities". That is true, but then life is tough for everyone and not just for persons with disabilities. Yet there is a difference. Our perception (i.e. an able-bodied person's perception) of the quality of life of persons with disabilities is seriously biased in such a way that we perceive persons with disabilities to be much less satisfied with life than they in fact are, and of course less satisfied than we are ourselves. These findings arise from research of Dr. John Bach from the New Jersey Medical School which he presented at a conference held in Toronto last April. Most people can assess their own quality of life (QoL) quite accurately. But when it comes to assessing the QoL of someone who is disabled the perceived QoL assessment ratings are very different.

The scale that you see in Figure 1

can be used to obtain a rating of Quality of Life.

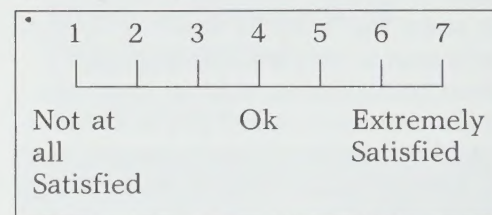


Figure 1

Bach used this scale and a number of general statements like:

Please mark on the above scale how satisfied you are with your life.

When Bach asked this question of some 620 health service providers their average response was 5.36, that is almost midway between Ok and Extremely Satisfied. However, when he asked the same people to rate how satisfied a person with disabilities would rate him/herself on this scale their response was 2.4, that is midway between Not at all Satisfied and Ok. When Bach asked persons with disabilities to rate their own QoL they scored an average of 5.11, more than a point above Ok and well into the satisfied side of the scale.

When I asked the people attending the planning meeting to respond to these two questions their responses were 5.5 for their own satisfaction level and a perceived level of (dis)satisfaction of 3.6 for their perception of the QoL of persons with disabilities.

What do these numbers mean for service provision in AAC and rehabilitation in general? We, other health service workers and most likely every able-bodied person in the world, think that persons with disabilities are quite dissatisfied with their lives. And we are totally wrong. Persons with a disability score, on average, somewhat lower on the 7-point scale but well beyond the midpoint (Ok or so-so).

You can understand that the predominant emotion or sentiment will be when a person with this distorted belief system (i.e. almost every able-bodied person) comes in touch with a person who is disabled. They will always feel pity or guilt or empathy where the person

with the disability would — I'm sure — much rather have us react on an equal emotive level, as friends, opponents, critics or partners.

Alternatives and Options

Vargo sketches a perspective for the 21st Century in which society's expectations of persons with disabilities will be higher so that they will be expected to be able to find and hold jobs, to live independently, to advocate for themselves. The very expectations will help to spur consumers and service providers to work towards better systems of integration and participation.

Persons with disabilities would have responsibilities exactly like able-bodied persons; and even though that sounds natural how many persons with disabilities do you know for whom this applies? Advocacy would become generic, no longer would we have advocacy groups for specific disability groups. Instead general issues would be championed by general advocacy organizations e.g. women's groups or seniors advocacy organizations. Persons with disabilities would be integrated in this aspect of life too.

Finally, with respect to employment Vargo believes that people with disabilities can aim for jobs that require a higher education, e.g. lawyer, engineer, professor or teacher. These jobs require virtually no physical manipulation, or none that cannot be automated or computerized.

The Revolution

Gary McPherson is president of the Premier's Council on the Status of Persons with Disabilities in Alberta, Canada. The title of his article is "Are you ready for the revolution?". The revolution that McPherson has in mind is taking place in the fields of medicine and rehabilitation, and more so in the latter. The revolution concerns the democratization of medicine or, for persons with disabilities, it is about acquiring equality, full integration, and real decision-making power about who gets which device, and when. Examples of the increasing power of consumers in Canada, both at the provincial and national level, are the establishment of the equivalent of Premiers Councils on the Status of Persons with Disabilities in, I

believe, six provinces and the emergence of national organizations such as the Canadian Association for Independent Living Centres (CAILC). These organizational initiatives are evidence of a systematic approach that is being followed to streamline the integration of persons with a disability into the community.

McPherson proposes five principles of the revolution. I find that these principles capture the essence of the revolution, but are also very helpful as tools to learn to live with this new order. I say learning to live with it, because that is undoubtedly what is required. Health care service workers that I know, even the ones who are most progressive in their concepts of empowerment, are still unaccustomed and often reluctant to relinquish control over the assessment, consultation, and device prescription process.

Five Principles

McPherson formulated five principles that characterize the consumer revolution.

(1) Equal status, personal contribution and inherent worth. This means exactly what it says. The person with disabilities must be treated as equal (friend, opponent, etc.). We must recognize the inherent worth of the person's contribution to society, our lives and other people's lives.

(2) Equity of Opportunity. This speaks for itself, and AAC and rehab technology can continue to be of real assistance here.

(3) Individual responsibility and personal control. This is a very difficult concept to accept for people in the AAC or rehabilitation service field. Think of people with disabilities being in control of their own device selection and purchase. A skilled clinician knows in how many ways a wrong decision can be made, and how expensive or annoying a wrong choice can be. Yet it is not the clinician who needs to speak daily with the VOCA, or who needs to communicate with a symbol board or sit in a particular wheel chair. It is the consumer who is the end-user of the product and so it would appear natural that the consumer makes the final decision, given of course as much advice as possible.

(4) Opportunity for full participation in community life. This princ-

iple, too, is obvious, but still some distance away from its full implementation.

(5) Consumers as consultants. The fifth principle encourages us to consider the clients (AAC device users or consumers). Once clinicians learn to follow the user's advice, the burden of making decisions for another person is turned into giving the best possible advice to the consumer. This is a much less powerful yet equally useful role for professionals.

Getting Ready for the Revolution

To conclude I will give a number of possible applications for McPherson's principles and Vargo's perspectives.

- Try not to polarize the field into us and them;
- For persons with disabilities, get out there and show off what you can do;
- For persons without disabilities, get together, work with persons with disabilities, ask them to work with you, ask for their opinion and listen to them;
- Organize the situation so that each person can do what he or she does best;

Know that consumers have more experience with devices and obstacles than you have.

Following these points, it will be very easy for you to learn to appreciate persons with disabilities as consultants and consumers.

Perhaps the most important part of allowing the person with disabilities, whether adult or child, to make decisions, choices, and to be responsible for these choices, will be that this process is excellent training for mature communication, and for living independently. □

References:

- Bach, J. (1991). The quality of life: Self perception. Beyond the I.C.U. III: Perspectives on Ventilation. Conference presentation, Toronto, Ontario, April 19, 1991.
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- MacPherson, G. (1990). Are you ready for revolution? *Canadian Journal of Rehabilitation*. 3 (3), 133-139.
- Vargo, J. (1991). Perspective on a different world. *Rehabilitation Digest*. Summer, p.15-17.

Reading Bliss is Easy

RUTH HARRINGTON

Learning to decipher the written form of our oral communication can be a complex process. However, for augmentative communicators who use the graphic representational system Blissymbolics to relay their thoughts and ideas, reading *their* expressive language is a much simpler task. The language system they use is already in its written form. This differs from those reading traditional orthography where it is necessary to make sense of letter/sound relationships to understand the words which will allow them to enjoy a story on their own. The challenge for Bliss users is to find books and materials written or translated into Blissymbols which will provide them with suitable and meaningful reading opportunities, no matter what their cognitive level or interests.

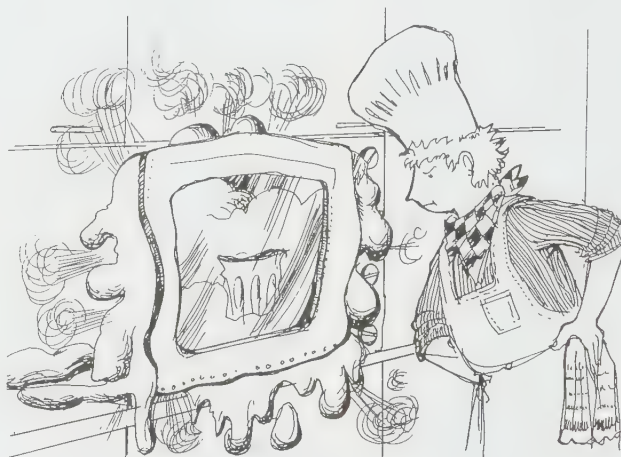
Marjolaine Moreau and Jean Roux, from Suresnes, France, and Roland Pavot, one of BCI's monitors who supported them, have been working to meet this need. Here are excerpts from two of their delightful creations for younger readers.

The first, *Benoit Cooks* is about a young boy who dreams about making a cake and everything goes wrong.



Benoît ^△○

Benoît cuisine.



○ ∅ ↑ ^ ↑ □ □ , | ^ □ ...

| ^ , | → □ □ + □ + | → ...

Le gâteau monte dans le four, il emplit le four...
il monte, il pousse la porte du four et passe à travers...

English translation

The cake rises in the oven, it fills the oven ... it rises, it pushes the oven door and spills out.

Blissymbols used herein are derived from the symbols described in the work *Semantography*, original copyright © C. K. Bliss, 1949.

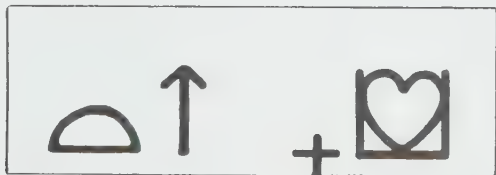
September 1982, C. K. Bliss granted an exclusive, non-cancellable and perpetual, world-wide license to Blissymbolics Communication International, to provide standards for the application of Blissymbols, for use by handicapped persons and persons having communication, language and learning difficulties.

The Versatility of Bliss

The marvellous part about Blissymbols is that they are a part of an expressive and written communication system, which has broad and unique capabilities for all ages or abilities and a logic that becomes more and more apparent as you use it. From the embellishments that make the symbols easier for very young users (Picture Your Bliss), through the developmental stages leading towards literacy, Blissymbols can also accommodate the needs of more mature and sophisticated users. To confirm this, one only needs to examine the human sexuality symbols (*Communicating Together*, Vol. 8, Numbers 3 & 4)

which are being used in the publication of a series of sex education books. The Blissymbols used in them can help non-disabled, learning-disabled and illiterate adults understand sexual concepts and the relationships between them.

The second book by Marjolaine Moreau and Jean Roux is at this more mature level. In this case, their efforts have given their readers, speaking and nonspeaking, the opportunity to learn about a historical event which is an important part of their heritage. "L'aube de la Liberté" is a factual story of the French Revolution.



L'aube de la Liberté. (The Dawn of Liberty)

Marjolaine Moreau
Jean Roux

Blissymbolics Communication International Distributors

Canada

Easter Seal Communication
Institute
250 Ferrand Drive, Suite 200
Don Mills, Ontario
M3C 3P2

In Québec, Canada

(French Materials only)
Association de Paralysie
Cérébrale du Québec Inc.
Centre de Ressources Bliss
525, boul. Hamel est, Suite A-50
Québec, Quebec G1M 2S8

United States

EBSCO Curriculum Materials
Box 1943
Birmingham, Alabama 35202
U.S.A.

Australia

Pro-Ed (Aust)
P.O. Box 735
Modbury, South Australia 5092
Australia

Netherlands

Bliss-symbolen
Communicatiecentrum
Revalidatiecentrum
"De Trappenberg"
Crailoseweg 116
1272 EX Huizen, Nederland

Spain

Pilar Such Acin
ASPACE
Apartado 55
20.080 San Sebastian, Spain

United Kingdom

Blissymbolics Communication
Resource Centre (UK)
Thomas House, S.G.I.H.E.,
Cyncoed Centre, Cyncoed Road
Cardiff CF2 6YD, U.K.

CATHY FAIRLEY

The Paraphrase is written for those who are moving into traditional orthography. It offers an independent reading opportunity for the growing reader. The Paraphrase is written by Cathy Fairley, former consultant, Easter Seal Communication Institute.

Hear Our Voices

This article was originally written by Kari Harrington in the last issue of *Communicating Together*, Volume 9, Number 1, 1991.

There is a new group for nonspeaking people and their friends. It began last fall. It is called Hear Our Voices. It is run by nonspeaking people.

The group has a board of directors. There are twenty users on the board. I am one of them. The board cannot meet face-to-face. But we will hold "meetings" using the mail, phone and fax. The board will help to decide the issues for the group to work on.

It will cost ten dollars to join Hear Our Voices. Each member will get a newsletter. We will look at issues, funding and special problems we all have. The goal of the group is to help us each be the best we can be.

If you want to join, please write to:

Hear Our Voices,
105 West Pine Street
Wooster, Ohio 44691 U.S.A.

Communicating Together announces New Publisher

Effective July 15, 1991, *Communicating Together* will be published by **Sharing to Learn** Publishers. The two principals in **Sharing to Learn** Publishers are Shirley McNaughton and Peter Lindsay, both of whom are well known in the field of augmentative and alternative communication.

After July 15, 1991, the new mailing address will be:

Communicating Together
P.O. Box 1762, Station R
Toronto, Ontario, Canada
M4G 4A3

Looking Back

ANN KENNEDY



Ann Kennedy is the director of the Easter Seal Communication Institute (ESCI) in Toronto, Ontario. She has been involved in the field of augmentative communication for many years, beginning in 1971 as a volunteer in the original Blissymbol class taught by Shirley McNaughton. Since then she has held a variety of positions with Blissymbolics Communication Institute and latterly with ESCI. One of her current responsibilities is editorship of Communicating Together.

It is with both pride and sadness that I write this perspective for *Communicating Together*. I take pride in reflecting back on the nine years of producing a magazine that has contributed to the growth of the field of augmentative communication. I am sad to think that this is the last issue for which I am responsible.

First the Bad News

This is the last issue of *Communicating Together* that will be published by the Easter Seal Communication Institute. For the past two years, ESCI has been operating as a department of The Easter Seal Society which has a mandate for providing services to physically disabled children and their families in the province of Ontario. ESCI does this by offering consultation and training to teachers and others in the educa-

tional field who are working with children who are nonspeaking. Unfortunately publishing a magazine for world-wide distribution falls outside the Society's mandate.

The last year has been financially difficult for many of us, and the Society is no exception. Faced with increasing demands for its services and a mounting deficit, it has been evaluating all its activities. It was with great reluctance that we decided that it was no longer feasible to continue publishing the magazine.

And Now the Good News

When I broke the sad news to Shirley McNaughton, she was of course distressed. After all, it had been her idea in 1982 that a magazine of this sort was needed, and it was her vision and determination that kept us going through rough times before. It wasn't long until she came back to me with a proposal that she and Peter Lindsay would take on the roles of volunteer co-editors under the name "Sharing to Learn". They have outlined their plans in the article on p.00. Easter Seals and I are delighted that *Communicating Together* can continue in this voluntary fashion and are more than willing to co-operate in assisting the new group to become established. All records, money from subscriptions, and materials will be turned over to them. Knowing the people involved in the new venture, I am sure readers will find the new magazine exciting and stimulating.

Beginning a Magazine

The original concept for a new magazine must be credited to Shirley McNaughton. Early in 1982, she identified a need for a publication that was *for* and *about* people who use augmentative communication systems, their families and the professionals who work with them. This meant the magazine had to be eclectic, with articles for a wide range of people and interests. As she said in the lead article in the first issue, "This publication will help bridge the communication gap,

and broaden community awareness of the nonspeaking person's needs and the ways these needs can be met." This has continued to be the focus of *Communicating Together* throughout its nine years of publication.

Serious planning began in the spring of 1982, when Shirley asked me to be the managing editor, a job that fitted with my title of Co-ordinator of Special Projects. Knowing nothing at that point about managing or editing, I was somewhat apprehensive. However, one of Shirley's greatest strengths is her ability to see in you things you don't know about yourself, and then to convince and encourage you to try. So, having been persuaded I could do it, we rather naively pushed ahead together.

We had meetings with magazine consultants and a designer. We chose Pat Thorvaldson, a freelancer, as our first editor. We had meetings about a magazine name, cover design, ink colour and the type of print to use. We chose a printer, Beacon Herald Fine Printing in Stratford, Ontario, and had numerous meetings with them, as they patiently taught us about the printing process. And last but by no means least, we had meeting after meeting with our editor and others about the actual content of the magazine.

After about six months of planning, we were finally ready to publish the inaugural issue. The publication date was aimed to coincide with the Second International Nonspeech Conference held at the Ontario Institute for Studies in Education (OISE) in Toronto, in November 1982. What better place to launch our new project! We made it, barely, as the magazine was delivered on the last day of the conference. The excitement of actually seeing it in print made up for any disappointment at the fact the accent colour turned out to be orange rather than red — a communication breakdown and lesson learned.

The cover story in that first issue was about two teenage girls, Kari Harrington and Ann Running, who had the opportunity to attend an

opening week concert at the brand new Toronto concert hall, Roy Thomson Hall. The concert featured Anne Murray, their favourite singer. The new hall purported to be fully accessible in all areas of the building (a relatively new idea in 1982) and the girls tested it out and agreed.

Another column featured in that first issue was "Family and Community" written by then fourteen-year-old Andrew Murphy, assisted by his father Mark. It's interesting that that column is still one of the most popular in *Communicating Together* only now it is written by Kari. Andrew has moved to the United States and is a student at Edinboro College in Pennsylvania. I still hear from him from time to time and can't help but be proud of his accomplishments.

One loyal writer who has been with us since the beginning is Geb Verburg, and his column "Research and Publications". In that first issue he discussed "Translucency Made Transparent", two terms that were rather new to the field of augmentative communication at the time, but which are in common use in 1991. Over the years Geb has written on a wide range of topics that have been at the cutting edge of the developing field. Readers have not necessarily agreed with him, but Geb's articles have nearly always stimulated thought and discussion. In the recent reader survey that we conducted, his column rated second only to "Family and Community" as one that people always read. I want to publicly thank Geb for his contributions to *Communicating Together* over the last nine years and thirty-five issues!

Communicating Together and Blissymbolics

Many people have assumed, because of our close association with BCI, that the magazine is really just about Bliss. True, we have always had "Blissymbol Talk" as the focus of the centre section. This is natural, I feel, given our roots. It also reflects the fact that there have always been new and interesting developments in Blissymbols that we have wanted to share with readers. We have, however, always looked for articles about other graphic systems, and have encouraged developers of

those systems to write about them.

In recent years, the advances in computer technology have led to new possibilities for graphics as applications have been developed to incorporate them in software for creating communication displays, story writing and literacy.

Before the days of common use of the personal computer, and long before the development of the Macintosh computer, our printer, Beacon Herald Fine Printing, became intrigued with the system of Blissymbols and the problem of incorporating them into print. In the early days of the magazine, this could only be done by reducing master photographs of the symbols to the required size and inserting them as artwork into the typeset copy — a very tedious and expensive procedure. They came to us with the suggestion that if we could find money to fund the project, they would be interested in working with us to develop a font for their Compugraphic typesetting machine which would allow Blissymbols to be set along with regular text. Funding was forthcoming from the Toronto Kiwanis Club, and the project was on! The patience and understanding of the Beacon Herald staff was unlimited as they worked through each symbol in the system ensuring the font would be perfect. Finally, in December 1984, *Communicating Together* was able to typeset Blissymbols as part of regular text (Volume 2, Number 4). This breakthrough was exciting not only for the magazine, but it enabled other Blissymbol publications to be undertaken in a much more efficient way.

It's hard to believe that in just seven short years, this technology has been surpassed. Now, Blissymbols and other graphic systems such as Picture Communication Systems (PCS) can be generated on a Macintosh computer to produce camera ready artwork for the printing process. That is how Blissymbols have, for the most part, been prepared for printing in *Communicating Together* for the last year.

Consumers and their Achievements

Preparing to write this article gave me an excuse to browse through the back issues and reminisce about

some of the cover stories we have featured. Most have been by or about young people who use some form of augmentative communication. I was struck by what a venturesome group they are. We have had stories about Justin Clark's camping trip through Europe in 1985. Then there was a humorous account by Alan King and Scott Palm from Seattle of their trip to the 1984 ISAAC convention in Boston. Anything that could go wrong did, but throughout they kept their sense of humour. Andrew Murphy wrote in 1987 about his wilderness canoe trip in northern Ontario. The lack of traditional means of communication certainly doesn't stop these people from getting around the world.

We have featured many stories about more and more successful integration of students who are nonspeaking into the regular school systems, particularly in North America. In many of these situations, the integration is helped when the student can use some form of technology. Benny Belair was the subject of one of the first of these stories we reported in 1983 when he used his Apple computer in the class, and even managed to keep statistics for the school's hockey program (Volume 1, Number 3).

Some articles have focussed on issues of concern to individuals. Nola Millin and Sylvia Mosher have both written on independent living at the university level — what help they need and what decisions they prefer to make themselves. There is a delicate balance between wanting to be independent, and recognizing that help is needed for some tasks.

John Dowling and Susan Odell of Toronto have written very moving articles about their individual encounters with death and how others around them reacted to them at this very emotional time. I have had several requests from other publications for permission to reprint these thought-provoking articles.

The ISAAC Connection

I realized how long *Communicating Together* has been going when I saw that it was in the September issue in 1983 (Volume 1, Number 3) that we announced the "birth of ISAAC" on May 19, 1983 in Michigan. Since that time we have had a long and

close association with that organization. We have reported extensively on all the conventions to date: Boston '84, Cardiff '86, Anaheim '88 and Stockholm '90. I have been privileged to attend all but Cardiff, and what an experience they were. The breadth of presentations is growing each year and it is getting difficult to see and hear all you want to in the time available. It is at these conventions that I have been able to track down interesting articles for our readers. Many of you will recall how I cornered you following a presentation and persuaded (or maybe strong-armed) you into agreeing to write for us. I thank all of you who co-operated, because it's your articles that have made *Communicating Together* so unique and eclectic.

Bouquets to Many

I thought it fitting to treat this, my last article as editor, as a "Perspective" because it does reflect the field from a point of view different than that of clinicians and professionals. We have been fortunate over the years to have had articles from academic leaders such as Lyle Lloyd, David Yoder and George Karlan to name but a few, and developers including Alan Newell, John Eulenberg and Bruce Baker. Manufacturers such as David Gordon and Barry Romich have shared their experiences with us too. Many clinicians, such as Caroline Musselwhite, Colleen Haney and Faith Carlson have contributed new ideas and teaching suggestions. The list is much too long to mention them all here, but each has played a role helping *Communicating Together* maintain its focus of providing news, stories and information about augmentative and alternative communication. I consider myself fortunate to have had the opportunity to know personally so many of these committed people. We have literally had writers from around the world: from India to Scandinavia, Australia to Israel, North America to Hungary and Poland.

For my own part, I confess I am proud of the reputation *Communicating Together* has attained. It would not have been possible without the support of many people over the years; from Pat Thorvaldson the first editor, followed by Sarah

Swartz in 1984 and 1985, to Barbara Reid, ESCI consultant who has been an exacting associate editor for the last three and a half years. From them all I learned so much. And, of course, there has always been the loyal help from my own support staff.

Throughout the nine years, Shirley McNaughton has been a constant. She never wavered in her commitment to the magazine; despite all her other activities, I could always count on her. To readers I say *Communicating Together* is in good hands with Shirley and Peter Lindsay as it enters its second decade. The field of augmentative and alternative communication will leap ahead in the 1990's, and with it will go *Communicating Together*. Good Luck! □

Looking Forward — A New *Communicating Together*

SHIRLEY McNAUGHTON
PETER LINDSAY

Shirley McNaughton, the first president of ISAAC, was formerly the Executive Director of the Easter Seal Communication Institute (ESCI). Since her retirement in 1989, she has been working on her PhD in Special Education at the Ontario Institute for Studies in Education (OISE). Peter Lindsay is a professor in the Department of Instruction and Special Education at OISE. He, too, has had a long association with ISAAC and is currently a board member and chair of Operations and Administration.

When we first learned that the Easter Seal Communication Institute would have to discontinue publishing *Communicating Together*, we selfishly thought, "What will the AAC community be like without its 'heart'?" for this is what *Communicating Together* has become for us! We knew we would greatly miss its human point of view; its user friendly format; its international perspective; its practical information directed to AAC users, parents and professionals.

We asked Ann Kennedy, *Communicating Together* editor, if some of the *Communicating Together*

stakeholders could be given the opportunity to problem solve with her. The result is a new editorial team and a new format, but the continuation of *Communicating Together*!

We are delighted at the number of interested persons who have agreed to become associate editors of the new *Communicating Together*! We look forward to working with them in providing our readers with information that responds to the needs of our ever-changing field. Here is what we are planning:

Peter Lindsay will be responsible for the *Feature* article and will be ensuring that topics relating to and important to augmentative communicators receive attention through the lead article. The first one will relate to "guided co-authorship" (who does the guiding?), written by the authors of *I Raise My Eyes to say Yes*, Ruth Sienkiewicz-Mercer and Steven Kaplan.

Kari and Ruth Harrington will be editors of *Living* — a section relating to day-to-day issues, as viewed by augmentative communicators and their families. They will be exploring such topics as growing up, transition to independence, sexuality, family relations and many more.

Colleen McGaffey and Robert Haaf will co-edit *Teaching and Learning* — a section directed to instructors and learners. Watch this section for issues relating to assessment, facilitating, teaching, handling technology, scheduling, etc. Colleen's and Robert's goal is to examine the many different dimensions of teaching as they consider persons with a wide range of learning abilities and styles.

Jeff Higginbotham will be the editor of *Consuming Technology* — a section devoted to technology for the 'consumer'. Within this section, there will be consumer reports, ideas for home made technology and descriptions of products providing information that the consumer needs to know.

Shirley McNaughton will be writing *Symbol Talk* — a new section, building upon Blissymbol Talk in the current *Communicating Together*. It will include a general tutorial on AAC graphics, discussing the many types and the new roles graphics are playing.

Geb Verburg will continue in his thought-provoking manner, editing

Contexts — a section that will explore a broad range of issues relating to AAC, from the perspective of a very interested rehabilitation professional.

Cathy Fairley will continue to edit *Paraphrase* — a section specifically designed to facilitate independent reading for those who require a controlled vocabulary. She welcomes your suggestions for those articles that AAC users would like to see paraphrased.

Leanne McLaughlin will be sharing ideas through *Resources* — a section that comes from our readers. This is everyone's opportunity to contribute suggestions for instruction, assessment, training, using AAC systems and even future articles in *Communicating Together*.

Carol Lynn Katsios will be editing *Potpourri* — a section responding to the need to address current topics and concerns that

may not just fit into any of the above sections!

We invite, and strongly encourage, those who are involved in AAC to contribute their ideas and opinions. We want each section of *Communicating Together* to reflect the input of augmentative communicators and those who are close to them. We decided against an "international section" because we want every section to be an international sharing!

We are excited about the new *Communicating Together*! We urge readers to contact any member of the editorial team with ideas about content or with article submissions. We want this to be your magazine! See you in September! □

Shirley McNaughton and
Peter Lindsay
Co-editors
The New Communicating Together.

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The new *Communicating Together* team at their planning meeting in Niagara-on-the-Lake, Ontario in February, 1991. From left to right in back row: Shirley McNaughton, Robert Haaf, Colleen McGaffey, Peter Lindsay, Ruth Harrington. Front row: Carol Lynn Katsios, Geb Verburg, Leanne McLaughlin and Jeff Higginbotham.

Communication Training Involving Facilitated Communication

Rosemary Crossley

Rosemary Crossley is an Australian teacher who has worked with people with severe communication impairments since 1972. She first used facilitated communication in 1977 with Anne McDonald who has athetoid cerebral palsy, and they co-authored a book, Annie's Coming Out. She has been Program Coordinator at DEAL Communication Centre since it opened in Melbourne in 1986.

DEAL (Dignity, Education and Language) is Australia's first centre solely devoted to the needs of people with severe communication impairments not due to hearing impairments. The centre has a multi-disciplinary team providing communication assessments and training, equipment loans, and software and hardware development and adaptation.

Students whose speech is not adequate for communication need to use other means of communicating and making choices. Equally, students whose fine motor skills are not adequate for acquisition of normal pen and pencil skills need a substitute, usually a keyboard or computer interface. Speech or fine motor skill impairments rapidly become severe educational handicaps if energetic measures are not taken to remedy them. Apart from their day to day effect on the student's classroom performance, these impairments make it extremely difficult to assess a student's actual abilities with any reliability.

Many students find themselves caught in a downwards spiral: assessed as significantly intellectually impaired as a result of their speech and motor impairments, they are placed in a school where their speech and motor impairments are seen as being the unavoidable corollary of their intellectual impairments. They are unlikely to receive an occupational therapy assessment, and speech therapy is

likely to be at a premium. The combined effect of continued failure, low expectation and lack of therapy is likely to cause deterioration or stagnation rather than the improvement in skills that is every teacher's aim. The students' behaviour is often as poor as their academic performance.

Since the opening of the DEAL Communication Centre in 1986 we have seen many students in this situation. "Sue" is representative. When she first attended DEAL she was fourteen, diagnosed as autistic, and assessed as having a verbal I.Q. of 50 (how this had been assessed was far from clear as Sue had no speech, poor fine motor skills and her eye-hand coordination very poor). She had been given training in manual signing and had acquired approximately 100 signs (more than many students, but still much less than the expressive vocabulary of a two-year-old signer). She used a typewriter with difficulty for simple copying tasks. She was thought to be reading at roughly a six-year-old level. When facilitated access to a mini-keyboard was provided to compensate for Sue's fine motor problems it quickly became clear that her literacy skills had been significantly under-assessed. Sue transferred from her special school to a high school at the start of 1988. She is now handling the regular Grade 12 program successfully and will be undertaking public exams at the end of the year. She is able to type and use her communication aid without support, but has difficulty sustaining the speed and endurance necessary for her heavy academic load without facilitation. Equally, without the initial facilitation she would likely still be attending a special school, presumed to be intellectually impaired.

Because of Sue's fine motor problems, neither signing nor handwriting provided her with an effective alternative to speech. Children who are not succeeding with signing or handwriting, both of which place high demands on fine motor skills, should be reassessed, with a view to finding another communication strategy with which

they can be more successful. The obvious alternatives all involve making a choice by pointing, either to real objects, or to pictures, symbols, words or letters. These may be used on communication displays, electronic communication aids or typewriters.

Even though pointing is motorically far less demanding than signing or writing, many students still require remediation before they can point accurately. All too often a student's failure to point accurately is seen as a reflection of intellectual impairment or ignorance, and a detailed assessment of the student's perceptual-motor status is not obtained. After seeing many students similar to Sue, students who required further communication augmentation, who required intensive manual training to acquire the necessary physical skills, the DEAL team devised a communication aid access and training program called facilitated communication training.

"To Make Easier"

To facilitate is to make easier. In facilitated communication training, the task of using a communication aid is made easier for a student. The degree of facilitation needed varies from child to child, ranging from an encouraging hand on the shoulder to boost confidence, to full support and shaping of a student's hand to enable him or her to isolate and extend an index finger for pointing.

Facilitation differs from other hands-on training methods such as graduated guidance and co-active movement in which the movements are performed by both student and teacher together, and it does not matter if the teacher's movement is stronger than that of the student. In facilitated communication it is vital that the choices made be those of the device user. The user's movement should be stronger than that of his or her facilitator, who gives the minimum assistance necessary.

Any student whose speech requires augmentation and whose hand skills are not adequate to achieve a level of expression matching his or her

receptive and internal language is a candidate for facilitated communication. Beware of putting the cart before the horse here. As assessment of students with severe expressive problems is so difficult, no student should be excluded from the training program on the basis of previous negative assessments. Often the training is a prerequisite for accurate assessment. Always give the student the benefit of the doubt. As facilitated communication requires both some hand skills and the potential for improvement in those skills it is not usually the method of choice for people with severe physical impairments.

Facilitated communication offers most to students who are ambulant, for whom an easily portable communication system that is accessed manually is necessary. To date successful users of facilitated communication include people diagnosed as intellectually impaired, autistic, and people with mild cerebral palsy. Regardless of diagnosis, all potential users have impaired motor skills which preclude use of handwriting or signing for more than the most basic communication, and which significantly impede their independent use of communication aids.

The immediate aim in using facilitated communication is to allow the student to make choices and to communicate in a way that has been previously impossible. As the student's skill and confidence increase, the amount of facilitation is reduced. The goal is for the student to be able to access the communication aid independently.

Common Problems Requiring Facilitation

1. Poor eye-hand coordination:

The student makes selections impulsively, without looking, or without allowing enough time between movements to scan the display and locate the target.

It is important that the student makes eye contact with the target before making a selection. At first the facilitator may have to restrain the student from moving until he or she is looking at the target area. Where the student is actually turning his head away from the target, the facilitator may need to assist him physically to maintain a midline, eyes down, position. If these

restrictions are enforced consistently, eye/hand coordination usually improves quite rapidly.

2. Low muscle tone:

The student's arm and hand are "floppy" or "heavy". He or she has difficulty raising the arm against gravity and muscles fatigue quickly.

The immediate remedy is to provide some kind of support. Support offered by the facilitator could include

- placing a hand under the aid user's forearm
- holding the user's sleeve or a wrist band
- holding one end of a rod while the user grasps the other end
- positioning the communication display so that the user can rest his or her forearm on the table or a typist's support — this is the optimum solution, but only suits users with no other accessing problems and only works while the user is sitting at an appropriate table.

If muscle tone is very low the student will do best when the device is positioned as low as possible to minimize the arm lifting required. Often such students are more independent in using devices when they are standing up. The long term remedy for low muscle tone is practice with the device, combined with an exercise program for arms and shoulders.

3. High Muscle Tone:

The student's arm feels tense, and movements are often too forceful, either over-reaching the target or pushing the device away. Usually the harder the student tries to perform, the more the muscle tone increases. This problem is often compounded by impulsivity (see 10 below).

Remedies include:

- shaking the student's arm until it feels floppy
- pointing to a target close to the body between selections, so that the student's elbow is flexed between selections
- allowing for regular pauses to give the muscles a chance to relax.

4. Index Finger Isolation and Extension Problems:

The student has difficulty in extending the first finger and holding back the other fingers. Users with this problem either point with all their fingers extended or use their middle finger (which is the longest). Remedies vary with the severity of the problem and include:

- an occasional reminder to keep

the other fingers back

— asking the user to hold a rod in his or her palm while pointing, to encourage flexing of the unwanted fingers (sometimes this prompts a reflex grasp in which case the index finger will also flex and the aim will be defeated)

— physical moulding of the student's hand by the facilitator (usually only done for a short period at the start of a training program)

— physically restraining the unneeded fingers — a simple method is to use a snug fitting sock. Make a small hole in its toe for the index finger, pull the sock down firmly over the student's hand so that the other fingers are bent and hold the sock in place by a piece of ribbon or velcro fixed around the wrist. This is a short-term solution. If pointing does not improve within a month further therapy advice should be sought.

— a curved or limp index finger may have to be splinted or a pointer may have to be substituted in the early stages of training.

5. Perseveration:

The student makes a selection and continues hitting either that selection or adjacent selections inappropriately.

The immediate remedy is to pull the student's hand back towards the body after each selection. Gradually this movement pattern becomes automatic and the student withdraws his or her own hand after each selection. Sometimes providing an alternate target between the student and the device can help develop the desired movement pattern.

6. Using Both Hands for a Task Only Requiring One:

If a student points to two items simultaneously it is hard to be sure which item (if either) was actually desired.

Every effort should be made to discover which is the student's preferred hand, and to encourage one-handed tasks be performed with this hand. Sometimes it is necessary to restrain the other hand or to devise other strategies to keep it out of the way. For example, a student may put her hand in her pocket, use it to hold a clutch purse or even sit on it!

7. Tremor:

In the short term, stabilizing the limb (either by the facilitator holding the student's wrist, or by the student holding one end of a rod held by

the facilitator) will assist. A long term program may involve the wearing of wrist weights while using the hands, or the performance of exercises suggested by an occupational therapist or physiotherapist.

8. Radial/Ulnar Muscle Instability:

The muscles of forearm, wrist and hand exert unequal pull on the hand or fingers. Sometimes the index finger swerves to one side as the student goes to point, leading to unwanted selections. The most common problem is for the student's index finger to move across in front of the other fingers. Often the hand drops down from the wrist as well, making the tip of the index finger invisible to its owner, who is then pointing blind.

Any remedy which restores the finger to view will help in the short term. In this case the facilitator can:

- suggest the student points as though pretending to shoot with the index finger
- try having the student hold one end of a rod while the facilitator holds the other in such a way that the student's hand does not drop
- manually correct the student's wrist and hand position

An exercise program to strengthen the student's arm and hand muscles is usually necessary to achieve long-term improvement.

9. Initiation Problems:

The student does not spontaneously reach out to the communication display. This may relate to self-confidence as much as to any physical problem, though it is especially common in children whose muscle tone is low.

A verbal prompt may be all that is required e.g. "What have you got to say?" In the earlier stages, a physical prompt such as a touch on the elbow is often necessary. The communication display should always be readily accessible to the student, and any spontaneous movement toward it should be reinforced with a positive response.

10. Impulsivity:

The student moves too fast to produce considered responses.

This is frequently, but not necessarily, associated with poor eye/hand coordination and the remedy is similar. Slow the student down and refuse to allow any selections if the eyes are not pointing to the target. Maintain a slight backwards pressure on the student's hand so that he or she is always having to push against your resistance to reach the communication display. (This is good practice with all facilitated students other than those with significantly lowered muscle tone, as the resistance has a stabilizing effect and reduces the chance of

the communication partner unintentionally directing the user to a selection.)

Moving Towards Independence

The time needed to achieve independent use of a communication aid is influenced by how frequently it is used, the severity of the problems the student started with, the self-confidence of the student, and his or her relationship with communication partners. As in learning any physical skill, regular practice is essential. It is probably not coincidental that the students who have moved most rapidly towards independence are those who have transferred into mainstream schools where they have had integration aides available to act as facilitators and pressure to match the quantity of work produced by the other students in the class.

As soon as a student starts to overcome one of these problems, the assistance given is reduced. The aim is always to withdraw support gradually so that the student continues communicating successfully and does not lose confidence.

Often students feel the need for physical contact beyond the time when this is strictly necessary to remedy physical problems (Oppenheim, 1977). Facilitators must accept this need for emotional support; if not, the student may withdraw and stop communicating and the gains made will be lost. A hand on the shoulder usually suffices until this too is faded and the student makes selections without any physical contact from the teacher. Verbal encouragement is important throughout the whole training procedure and is sometimes needed even when physical contact is no longer required.

Remember that a device user's need for facilitation will vary from time to time. When tired or unwell many device users have reduced physical control and may need more support than usual. Equally a user's skill will be affected by nervousness, so a student who does not require any physical contact when communicating in a small group may need a hand on the shoulder when communicating in public. Often device users who are starting to communicate with new partners initially appear to regress,



Mark Petterlin uses a typewriter at his school facilitated by his aide. He holds a rod to ensure index finger isolation and to compensate for his low muscle control.

seeking a degree of support that may have been discontinued months ago with their previous partners. This must be accepted if the interaction is to succeed. Support can be faded rapidly once confidence is established.

Literacy

Facilitation in itself is not directly connected with typing or literacy. It is a means of training manual selection skills that can be used in any situation in which choice-making is needed — selecting a chocolate from a box, choosing an item from a menu, making choices in a supermarket, pointing to body parts on a doll, matching pictures, etc. All of these activities require similar eye/hand skills. Nonetheless, many users of facilitated communication have learned to use keyboards and this has been an exciting outcome of this program.

Most students who have attended DEAL have had considerable exposure to written language if not to formal literacy training. However, like Sue, their expressive impairments have prevented any literacy skills they have acquired from being recognized. When sixteen-year-old "Joe" used a typewriter with facilitation to show that he could read and spell his mother said "Now I know why he takes his father's paper every night!" and she was not alone. Many teachers

and parents reported that students were showing an interest in written material — notices, books, papers, magazines, TV commercials that they found inexplicable until the students found a means of expression, via facilitated communication training. This enabled them to reveal that they had acquired reading skills. For this reason, it is important that students be given open-ended assessments when they enter a communication program and not be prejudged on the basis of their previous performance or labels. □

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ISAAC Call for Papers

The Program Committee for the 1992 ISAAC Biennial Conference, Philadelphia, Pennsylvania, invites proposals for presentations to be offered at the 1992 Conference. The Committee welcomes submissions on all AAC-related topics and encourages submissions from consumers as well as those working on behalf of consumers. All proposals must be received by September 30, 1991 in order to be considered.

The Program Committee will be guided in the selection of proposals by the criteria of quality, content area, significance, and program balance. Only unpublished papers may be presented. The 1992 Biennial Conference will offer presentations in a variety of formats. Those wishing to submit proposals for traditional platform presentations, miniseminars, poster sessions, or videotape presentations should submit a completed proposal form on or before **September 30, 1991**. Authors will be notified by January 1991 regarding the status of their submission.

Submission of a proposal is a commitment to register for and attend the conference. Only proposals received by September 30, 1991 will be considered. Proposals that are incomplete or that do not follow the format prescribed in the guidelines will be returned to the author.

Deadline date for submission: September 30, 1991.

Proposals should be mailed to:
Program Committee
1992 ISAAC Biennial Conference
Applied Science and Engineering Laboratories
A.I. duPont Institute
1600 Rockland Road
Wilmington, DE 19899 U.S.A.

For complete information and guidelines for submitting proposals contact:

ISAAC
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Toronto, Ontario
Canada M4G 4A3



COMMUNICATION OUTLOOK

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SCHEDULE OF EVENTS

ESCI Special Interest Seminars

In Toronto, Ontario

The Easter Seal Communication Institute (ESCI) holds a series of seminars throughout the year on a variety of topics related to the application of augmentative communication.

Fall Schedule will be available in late June. Among seminars will be:

- September 26, Adapting Toys
- October 3, Selecting Graphics for Communication Boards
- October 8, Programming for an Augmentative Communicator in the Classroom
- December 6, Using Interactive Games to Promote Early Communication

Contact: Training Coordinator, Easter Seal Communication Institute, 250 Ferrand Drive, Suite 200, Don Mills, Ontario M3C 3P2. Telephone: (416) 421-8377 ext. 2205

Technology Sessions at Summer Camp

In Georgetown, Colorado

- July 27 - August 2, 1991

Two camps are being offered at the same time: one camp is for augmentative device users, siblings and professionals who work with them. The second camp is for adaptive firmware card users and professionals or parents who work with them.

Contact: David Schmitt, Director, Center for Adapted Technology, Colorado Easter Seal Society, 5755 W. Alameda, Lakewood, Colorado 80226 U.S.A. Telephone: (303) 233-1666

Southeast Augmentative Communication Conference

In Birmingham, Alabama

- October 4-5, 1991

Contact: Pamela Elder, Co-ordinator, 2430 11th Avenue North, Birmingham, Alabama 35234 U.S.A. Telephone: (205) 251-0165

State of the Art Conference: Augmentative and Alternative Communication

In West Lafayette, Indiana

- October 10-12, 1991

Co-sponsored by ISAAC in conjunction with the annual NSSLHA Crossroads Conference on Communication Disorders. Presentors include: Carol Cohen, Shirley McNaughton, Hans Van Balkom, Richard D. Steele and David Koppenhaver.

Approved for ASHA continuing education credit.

Contact: Tom Robertson, Division of Conferences, 116 Stewart Center, Purdue University, West Lafayette, Indiana 47907 U.S.A.

Telephone: (317) 494-7220

6th Annual Minspeak Conference

In Minneapolis, Minnesota

- October 14-15, 1991

Contact: Prentke Romich Co., 1022 Heyl Road, Wooster, Ohio 44691 U.S.A.

Telephone: 1-800-262-1984

Closing The Gap Annual Conference

In Minneapolis, Minnesota

- October 17-19, 1991

Contact: Closing The Gap, P.O. Box 68, Henderson, Minnesota 56044 U.S.A.

Telephone: (612) 248-3294

Augmentative Communication: Light Tech to High Tech

In Toronto, Ontario

- November 4-5, 1991

Delta Chelsea Inn

The use of technology to develop play and communication skills.

Presentors: Caroline Musselwhite and Linda Burkhart.

Contact: Bloorview Childrens Hospital, 25 Buchan Court, Willowdale, Ontario, Canada M2J 4S9

Telephone: (416) 494-2222 ext. 313

Technology for Everyone Conference II

In Chatham, Ontario

- November 19-21, 1991

Best Western Wheels Inn

Contact: Paul McPhail, Southwestern Regional Centre, R.R. #1, Blenheim, Ontario, Canada N0P 1A0

Telephone: (519) 676-5431

About the Publisher

The Easter Seal Communication Institute (ESCI), has worked since its inception toward enhancing the lives of nonspeaking people. Operating as a department of The Easter Seal Society, Ontario, ESCI focuses on supporting augmentative communicators and their families and the professionals who work with them through its strategic goals.

1) Using a collaborative consultative model, to develop and implement services to improve the quality of education for nonspeaking children and young adults.

2) To educate, inform and increase the awareness of the community about the needs and abilities of nonspeaking children and young adults.

3) To contribute to and participate in the growing field of augmentative and alternative communication.

4) While supporting a number of communication systems, to recognize the system of Blissymbolics as a valuable means to advance augmentative and alternative communication.

AVAILABLE IN CANADA FROM ESCI

Easter Seal Communication Institute distributes many materials from

Mayer - Johnson Company NON-SPEECH COMMUNICATION PRODUCTS

Symbol Books

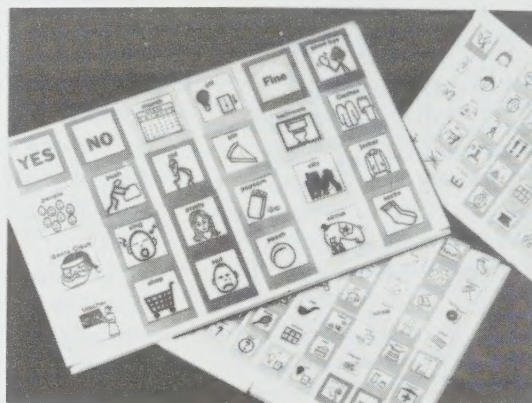
The Picture Communication Symbols

Books I and II

PCS Books I and II
(Black on White Stamps)

PCS Wordless Edition

Computer Programs



The Communication Board Builder
Boardmaker

Instructional Books

Listen to This
This is the One I Want
Stories About Me

What's in Your Home?
What's in Your Community?

Instructional Kits

Life Experiences Communication Kit

Holiday Kit

Games

Food Picture Bingo

Clothing Picture Bingo

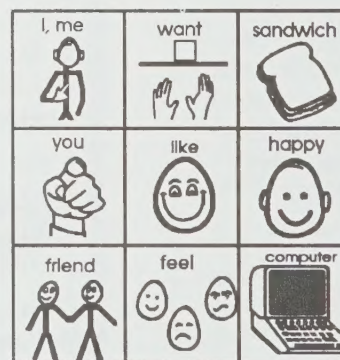
Training Materials

The Practice Communication Cards

Communication Training Board Kits
(formerly called ICS Boards)

Symbol Display Materials

Pocket - Sized Communication Book



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